

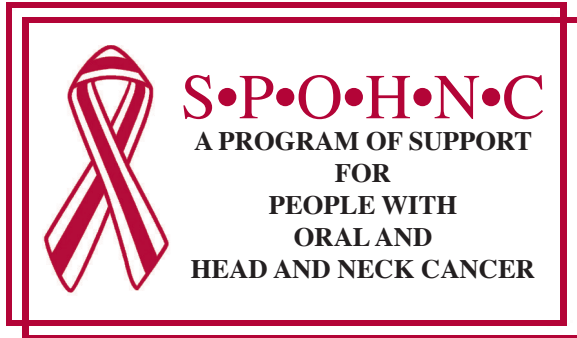
NEWS FROM S·P·O·H·N·C



VOL. 27 NO. 3

SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER, INC.

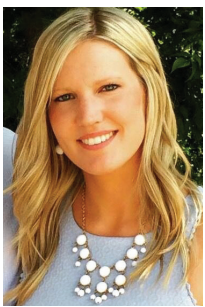
NOVEMBER 2017



Head and Neck Cancer Survivorship Part II: Other Essentials

Liza Murray, APRN & Allen M. Chen, MD

We're back! We'd like to expand on our survivorship topics from September's newsletter and highlight more survivorship challenges for head and neck cancer patients. We appreciate the feedback and insight from our part I article. We know that many survivors are affected physically, psychosocially, spiritually, and financially. Here are 5 additional topics of consideration in survivorship. We hope to bring recognition to these topics so survivors know they are not alone.



Financial Toxicity/Burden

Any cancer diagnosis can cause substantial financial impact among patients and caregivers throughout the trajectory of the illness. Survivorship can expand the time frame of expenditures due to patients living longer but still dealing with the sequela of treatment. Not only is the patient impacted, the caregivers and family are as well. Factors influencing financial constraints include increased direct out-of-pocket expenses, increasing health care costs, costs associated with changes in diet and nutritional supplements, supplies, loss of income secondary to decline in functional status, job loss, purchasing new clothes because of weight fluctuations, medications, childcare, increased utility bills, vehicle expenses, fuel, hotel stays, etc. Often patients demonstrate strategies to mitigate their financial burden, including reductions to other



health-related areas, clothing, food, and leisurely activities. At extremes, patients have reported house repossessions and home refinancing. The assessment of impact on financial distress on overall quality of life and suffering are of paramount importance. Financial burden is associated with anxiety, depression and poor quality of life. As providers, it is important that we refer patients and caregivers to social work/financial assistance counselors who can help navigate through assistance and resources per institution. In addition, financial assessment tools should be utilized more to assess this domain and help us better understand what is happening to our patients to ease suffering and improve quality of life.

Coping with Role Transitions at Home

Morbidity has been well documented among head and neck cancer survivors as discussed in survivorship part I of this discussion. What happens when survivors integrate back into home life as a parent, spouse, sibling, grandparent, professional, etc.? This transition often brings a different cascade of stressors to the survivor. There is moderate concern about cancer affecting the parental role, in terms of the usual practical things parents do for their children, but also the emotional consequences for the child. Parental role concerns expand to impact of mood, physical limitations, and changes in their routines. As involved the provider team is integrating survivors back to life, caregivers are just as important in this transition. Caregivers as well experience distress in this transition period. Caregivers and patients adapt to new roles during active treatment and now there is a need for another set of role changes or adaption that call for changes in demands of social, work and other relationships. Some institutions have a psycho-oncology team dedicated to improving the mental health of survivors and their caregivers. It involves everyone in the support system: caregivers, spouses, children, couples, and family. The care team helps families communicate better, acknowledge the situation, finding different ways to approach problems, and encouraging caregivers to take care of themselves.

There are challenges transitioning back to work for survivors. Rehabilitation programs after treatment can help lessen the anxiety of returning to work. Rehabilitation specialists help survivors seek supportive interactions with the environment that are essential to enable the ability to work. Survivors should be proactive with employers and help set reasonable expectations and provide realistic plans for work to be successfully completed. Physical exercise has been shown to positively influence return to work and work performance.

Sleep

There is a high prevalence of poor sleep quality in head and neck survivors. Sleep can be affected by depression, anxiety, pain, dry mouth, alcohol consumption, tracheostomy tube, feeding tube,

Find SPOHNC on Facebook



BOARD OF DIRECTORS

Nancy E. Leupold, MA, Survivor, Founder & President Emeritus
James J. Sciubba, DMD, PhD, Vice President
Walter E. Boehmler, Treasurer
Gail Fass, Secretary
Dorothy Gold, MSW, LCSW-C, OSW-C
Eugene N. Myers, MD, FACS, FRCS Edin (Hon)

EXECUTIVE DIRECTOR
Mary Ann Caputo

MEDICAL ADVISORY BOARD

David M. Brizel, MD <i>Duke University Medical Center</i>	Jed Pollack, MD <i>Northwell Health</i>
Allen M. Chen, MD <i>University of Kansas School of Medicine</i>	Karrie Zampini Robinson, LCSW <i>Fighting Chance, Sag Harbor, NY</i>
David W. Eisele, MD, FACS <i>Johns Hopkins Univ. School of Medicine</i>	David L. Schwartz, MD <i>The Univ. of Tennessee Hlth. Sci. Ctr.</i>
Bonnie Martin-Harris, PhD, CCC-SLP <i>Medical University of South Carolina</i>	James J. Sciubba, DMD, PhD <i>Greater Baltimore Medical Center</i>
David Myssiorek, MD, FACS <i>Jacobi Medical Center</i>	Elliot W. Strong, MD, FACS, Emeritus <i>Memorial Sloan-Kettering Cancer Center</i>
David G. Pfister, MD <i>Memorial Sloan-Kettering Cancer Center</i>	Everett E. Vokes, MD <i>University of Chicago Medical Center</i>
Randal S. Weber, MD, FACS <i>MD Anderson Cancer Center</i>	

NEWSLETTER EDITOR
Chris Leonardis

News From SPOHNC is a publication of
 Support for People with Oral and Head and Neck Cancer, Inc.
 Copyright ©2016-2017

DISCLAIMER: Support for People with Oral and Head and Neck Cancer, Inc. does not endorse any treatments or products mentioned in this newsletter. Please consult your physician before using any treatments or products.

IN THIS ISSUE

Survivor News.....4
 Time For Sharing.....5
 Head and Neck Cancer News.....7
 The Recipe File.....8
 Give Thanks.....9
 Chapter News.....10
 Chapters of SPOHNC.....11

continued from page 1

and functional disabilities. Sleep related breathing disorders such as obstructive sleep apnea is common in patients with tumors in the head and neck region. Daytime fatigue and sleepiness are common complaints and can have detrimental effects on quality of life. Anatomic distortion from the tumor and/or treatment may predispose survivors to obstructive sleep apnea. Referral to a sleep specialist is one intervention that may benefit head and neck survivors. Mindfulness-based stress reduction programs are available as an app on mobile devices. Yoga, tai-chi, exercise, and meditation can improve sleep disturbance. Medications can also assist.

Sexual Function

Sexuality is a fundamental, life-affirming experience that can profoundly be affected by cancer treatment. Although there is controversy regarding the extent and nature of sexual problems most reports confirm that cancer and its treatment have deleterious effects on sexual function among survivors. Decreased desire, fear of performance and decreased satisfaction have been reported among survivors. Poor self-image, increased isolation and disfigurement are commonly mentioned as a barrier to head and neck cancer patients who have undergone surgery. Disfigurement acts as a physical barrier between the subject and partner thus hindering sexuality within the couple. The rise in human papilloma virus (HPV) head and neck cancer has raised complicated issues for survivors and partners, including feelings of guilt and responsibility as well as questions about transmission and allowable sexual practices. When sexual problems go unaddressed, survivors can interpret this to mean that sexual dysfunction falls in the category of treatment related collateral damage that must be endured. Perhaps this is one of the most unfortunate misperceptions that survivors live with - a mistaken understanding that there are no effective treatments for sexual dysfunction after cancer. Survivors and partners often live for years with this issue weighing heavily on their mind and for those who have poor communication skills or relationship vulnerabilities a recommendation for intensive intervention such as couples counseling may be particularly helpful. We know that more work is needed to better understand the impact of systematic approaches helping patients manage sexual function. Strategies to promote sexual function after cancer treatment include medications, couples-based psychotherapeutic and psycho-educational interventions. Your treatment team may have resources for referrals to urologists, gynecologists and sexual health psychologists who are knowledgeable about sexual medicine. The first step is to simply acknowledge this aspect of life in survivorship like all other areas of function, no different than pain, sleep and fatigue.

Pain Management

Pain medication plays an important role in the interdisciplinary management during head and neck treatment and post treatment period for survivors. Pain should be as aggressively managed as their cancer is. Survivors are often faced with many questions regarding narcotic use and coming off them: when and how, uncertainty and anxiety, will the pain return, the pain is gone but the medications are useful for sleep and numbing other parts of life because a cancer diagnosis was already too much, stigma and fear, societal changes and norms, addiction and mental pain. Long term use of

continued on page 3

continued from page 2

narcotics causes a dependence for the body. Stopping narcotics cold turkey is not advised and should be tapered slowly under the direction of your provider. Even with a slow taper patients will experience some form of withdrawal and some will resort back to taking their pain medications regularly to avoid the feelings. Survivors often mention the most challenging post treatment task is coming off narcotic pain medications. Withdrawal symptoms can be uncomfortable but generally not life-threatening and will go away. Withdrawal deserves more attention as survivors often feel they've reached a set back in their recovery when experiencing withdrawal or feel ashamed like they've led themselves to being "hooked on opioids." Withdrawal symptoms include agitation, anxiety, muscle aches, restlessness, extreme fatigue, difficulty sleeping, sweating, abdominal cramping, nausea, vomiting and diarrhea. Withdrawal can last a few days up to a week, though some report longer. There are medications that can help counteract withdrawal symptoms such as clonidine. Clonidine can reduce anxiety, agitation, muscle aches, sweating, and cramping. Acetaminophen or ibuprofen can help aches. Meclizine or dramamine can help nausea. Imodium for diarrhea. Dehydration can be problematic, hydrating and flushing the body with fluids are essential during this period.

We also understand that not all survivors will be able to completely come off pain medication due to chronic tissue damage from the cancer and/or treatment. Pain management teams specialize in maximizing quality of life and managing pain with many strategies. Pain management teams are often approached under the direction of multiple disciplines (nursing, social work, physician, advanced practice providers, case managers, occupational therapy, physical therapy, psychologists, and nutritionists). A referral from your oncology team should be considered for chronic pain management.

Post Traumatic Growth

With the high level of morbidity that comes with head and neck cancer treatment one may question how could anyone find having such a disease a positive event? We've all heard of post-traumatic stress disorder (PTSD) which is well described in the literature, even for cancer survivors. PTSD can be described as the negative result of an

extremely troubling event. What you may not be familiar with described in recent literature for head and neck survivors and other cancers is post traumatic growth and benefit finding. Both can be described as the acquisition of benefit from adversity and growth with which individuals coping with the aftermath of trauma reconstruct or strengthen their perceptions of self, others, and meaning of events. It can be described as the experience of significant positive change arising from the struggle with a major life crisis such as cancer diagnosis and enduring treatment. Survivors with "benefit finding" often feel an increased sense of personal strength, more rich existential and spiritual life, and rearrangement of priorities. Social support and social connectedness benefit this acquisition. Head and neck support groups and organizations have a substantial impact on promoting and restoring physical and emotional health. It allows a sense of relating to others who've underwent similar treatments. SPOHNC has more than 130 Chapter support groups across the country where you can find help, hope and support.

Wrap Up

As if the diagnosis was not enough, coping with the financial hardships, role transitions, sexual limitations and disfigurement, restless sleep, and trauma of cancer continues to impact quality of life in survivors. The comfort and lifestyle of financial security can be swept right from underneath you. The profound journey one takes through diagnosis and treatment ultimately impacts the mental and physical challenges of transitioning back into a parent, spouse, or professional role after treatment. The questions surrounding narcotic use and coming off are often surrounded by uncertainty, fear, isolation, and anxiety. The adversity hypothesis of "what doesn't kill you makes you stronger" suggests that people can use adversity to develop as human beings through traumatic experiences. Validation that comes from acknowledgement in these survivorship issues is enormously powerful and provides a key step in the delivery of genuine whole person survivorship care.

Editors Note: Dr. Allen Chen is Professor and Chairman in the Department of Radiation Oncology at the University of Kansas School

of Medicine. He is a graduate of Cornell University, earned his Medical Degree from Yale University School of Medicine, and completed residency training at the University of Texas - MD Anderson Cancer Center and the University of California, San Francisco, School of Medicine. Dr. Chen is a leading expert in the management of head and neck cancers and is a frequently invited speaker for conferences across the world. He has particular interests in clinical trial development, medical education, and bioinformatics.

Liza Murray is a nurse practitioner in the Department of Radiation Oncology at the University of Kansas School of Medicine and has a particular interest in survivorship and quality of life for patients undergoing cancer care. After completing her Bachelor of Science degree at the University of Kansas, she earned a Master of Science Degree in nursing at the University of Kansas. Liza was the recipient of the Colleen P. Kosiak Clinical Excellence Award during her master's program and has also been honored with the "Outstanding New Graduate Nurse Award" and the "Hematology and Oncology Nurse Excellence Award" during her tenure at The University of Kansas Hospital.



Have an Idea?

***Have an idea
for a Feature Article topic?***

*"News from SPOHNC" continues
to seek out the best and most
current information for you,
our readers.*

*If you have a topic you'd like to
read about in the Spring, please
e-mail us at info@spohnc.org
and let us know.*

We want to keep you informed!

"Like" SPOHNC on Facebook

Survivor News

Halloween Fun Across the Country

Survivor, SPOHNC Dallas, TX Chapter attendee and dear friend of SPOHNC, Dave Noble recently shared this photo of himself having some Halloween fun – what a zest for life (and a love for pumpkins)! Dave has been sharing “punkin’ man” with trick or treaters who visit his home, for 25 years now. It’s amazing how punkin’ man hasn’t aged! Dave told us that he had more than 100 trick or treaters this year, despite the rainy weather.



Dave’s son, Chad, is a proud player for

the Chicago Cubs (as if we didn’t know from this photo?), so this year was especially intense for the Noble’s during the playoffs and the World Series. Seems there was a little healthy competition, as Chad and the Cubs are National League so he was pulling for Dodgers but the Texas Noble’s were pulling for Houston as they had such a bad time with the hurricane and they have many friends

down in the Houston area. All’s well that ends well. No hard feelings in the family after all – that’s true sportsmanship!



Ahoy Matey! - SPOHNC’s Syosset, NY Chapter surely has some fun lovers among them. We know wherever this couple was for Halloween, a good time was had by all – and there surely was music! Frank (survivor) and Carrie (caregiver)

Marcovitz are always the life of the party. They can be found wherever there is fun, and their customary enthusiasm shows here. Shiver Me Timbers!!

HEAD AND NECK CANCER NEWS

Rate of Dysphagia Determined by

Constrictor Muscle Radiation Dose in Head and Neck Cancer

November 28, 2017 - Dysphagia is a frequently occurring toxicity experienced by patients with head and neck cancer who receive chemoradiation.

The rate of grade 2 and grade 3 dysphagia among patients with head and neck cancer is determined by patient age, disease site, and the mean radiation dose administered to the total constrictor muscle volume, according to a study published in Clinical Cancer Informatics.

Dysphagia is a frequently occurring toxicity experienced by patients with head and neck cancer who receive chemoradiation – particularly to the pharyngeal constrictor muscles and supraglottic and larynx – but there is a lack of data elucidating the dose threshold before dysphagia occurs.

For this study, researchers assessed the outcomes of 424 patients with oropharyngeal, nasopharyngeal, hypopharyngeal, or laryngeal cancer who received modern intensity modulated radiotherapy and chemotherapy.

The median follow-up was 33.3 months. Grade 2 or worse dysphagia was observed in 9.7% of patients and grade 3 or worse dysphagia was observed in 5.2% of patients. The mean doses to the total constrictor muscle ranged from 30.1 to 85.7

Gy (median, 61.2 Gy). A 3.4% increase in the predicted rate of grade 2 or worse dysphagia per Gy was observed.

The mean threshold total constrictor doses resulting in less than a 5% rate of grade 2 or greater and grade 3 or greater dysphagia were lower than 58 Gy and 61 Gy, respectively.

The authors concluded that “the ability to calculate personalized probability of late dysphagia in these patients would be valuable in facilitating treatment planning as well as for clinicians to identify a subset of patients with increased risk of late dysphagia for early intervention.”



photo courtesy of caregiver, PJ Jordan

Great Stocking Stuffer!

SPOHNC’s Oral, Head and Neck Cancer Awareness Wristband!



Purchase at a special discounted price of 5 for \$10.

These wristbands were created to raise awareness and show support to the thousands of patients, survivors, caregivers and healthcare professionals who have endured the journey of oral, head and neck cancer.

Call 1-800-377-0928 or go to www.spo-hnc.org to place your order.

“The wristbands I ordered are already gone - please send me more of these great gifts that promote awareness as soon as possible!”

~ John K.

Shop with AmazonSmile to Support SPOHNC

Time for Sharing...How Did I Get Here?

So how did I get here? Early in 2009, I had not too long before celebrated my 30th birthday with friends and family. I began having pain in my upper teeth that radiated through my face. Thinking that I might have a cavity or something, I went to see my dentist. He told me that I had a sinus infection and that I should take some antibiotics. He also said that my gums seemed a little soft which was probably nothing but that I should follow up on it. I decided to contact my primary care physician for a follow up and he essentially said the same thing, "sinus infection." He prescribed two different types of antibiotics and sent me on my way.



Now I didn't think there was anything strange about any of this because I had at least one sinus infection a year and this was a normal thing for me. But this time was different...the pain eventually lessened, but did not completely go away. In addition to the dull pain, I noticed a lump in the upper part of my gums. I went back to the PCP and he suggested that I have a CT Scan. I still remember sitting in that room waiting for my scans not knowing that my life was about to change forever. After completing the CT and the doctor getting the results, he wanted me to immediately see an ENT specialist. He couldn't tell me much except that he had some concerns about what he saw in the CT scan and I needed to see a specialist. I met with an ENT and he let me know that my scans showed my right maxillary sinus completely full of some mass. He wasn't sure exactly what but it was clear that it could be serious. He ordered a surgical biopsy to find out more details.

On Thursday June 4th, 2009, I had a surgical biopsy done on my right and left maxillary sinuses. After doing the surgery, the surgeon felt pretty confident that it was something other than cancer. At least that was his initial response. We waited through

the weekend to get the actual results but were pretty positive because of the optimism of the doctor.

On Monday, June 8th, my life changed forever. The doctor called my wife with horrible news. I will never forget that day standing in the middle of a department store seeing my wife mouth the words "cancer" to me. I was in shock; I took the phone from her so I could talk to the doctor myself. He told me that they found squamous cell cancer cells in my right maxillary sinus. The cancer was so aggressive that it had gone through my palate and started to protrude out of my gums. We were so confused and distraught. We left everything in the store, grabbed our 2 year old and went to the car. We just sat in the parking lot of that department store, crying. That's all we could do in that moment.

All I was thinking was how could I, a healthy non-smoking 30 year old male in good physical shape, have cancer? And sinus cancer at that - something I had never even heard of.

After we collected ourselves, we immediately called family and friends to let them know what was going on. Some of our closest friends came over within hours just to sit and pray with us. Although I was scared and unsure of what the future would bring, there was this small bit of internal faith that I had, that told me everything was going to be ok and that I was going to get through this. I flash backed to a guy I heard on the radio earlier that year who was in the sports world and fighting cancer. I remember thinking; wow this guy is so positive and upbeat about his experience even though it's extremely hard. I said to myself, if I ever had to go through something like that, that's how I would want to do it. Little did I know, that thought was going to be challenged the same year.

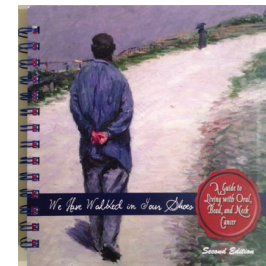
Fast forward to treatment. After meeting with a series of doctors, I landed with the right team that I needed at that time. They came up with a plan of treatment and we moved forward. I had major surgery - a right maxillectomy and neck dissection to remove the cancer and any possible impacted lymph nodes. Then all within the same surgery they did a fibula free flap replacement using the bone in my leg to

continued on page 6

**SHARE
YOUR
STORY**

SPOHNC is seeking Sharing Stories for the upcoming issues of "News from SPOHNC." If you'd like to share the inspiring story of your cancer journey, contact SPOHNC at info@spohnc.org or call us at 1-800-377-0928.

GET YOUR COPY NOW!



We Have Walked In Your Shoes: A Guide to Living With Oral, Head and Neck Cancer Second Edition

- Contains the basics about the symptoms and diagnosis of head and neck cancer, types of treatment and common side effects.
- Offers a section to list your healthcare team, a personal calendar and journal, diet and nutrition information, and a list of resources.
- Beautifully illustrated with impressionistic paintings of the 1800's.

Go to www.spohnc.org to purchase a single copy for \$14.95 includes shipping and handling.

Bulk order pricing - 25+ books \$13.50/book and 50+ books \$12.50/book includes shipping & handling. For bulk orders please call 1-800-377-0928 or email us at info@spohnc.org.

"We Have Walked In Your Shoes" is a tremendous resource for OHNC patients."

~ Valerie T.

Share SPOHNC on Facebook

continued from page 5

craft a new jawbone and tissue from my leg to create a new palate. I was in surgery for almost 12 hours! After the surgery I endured 3 months of chemo and radiation. I had two different types of chemo weekly and radiation every weekday. I continued the treatment until I could no longer carry on because the chemo was so strong that it was causing me to lose my hearing. My doctors wanted me to go for the strongest course of treatment because I was young and they wanted to be sure there was no cancer remaining in my body.

The treatment was one of the hardest things I've ever done in my life. I lost my sense of taste for a while, I had sores and breakouts in my mouth, throat and on my face. I could no longer eat because of the pain and had to be put on a feeding tube for nutrition. I was tired all the time and just felt bad most of the time. Because of the surgery, I lost the feeling in my upper lip and part of my face. My nose would drain sometimes and I didn't even know it. I was often embarrassed about my appearance but I was determined that I would not stop living my life. So, I went on with my family and my life as if things were normal even though I knew I looked horrible.

As I was going through all of this, my beautiful wife was busy trying to take care

of me, a two-year-old and keep herself healthy given that she was pregnant. She started to have complications while I was going through my treatments. At one time, we were both in the hospital at the same time on different sides of town.

What got me through all of this? My faith, my desire to see my children grow up with a father, and the support of my family and friends. I've always had a strong sense of purpose and I just believed from beginning to end that there was more for me to do on this earth and it wasn't my time yet. Despite what I felt I looked like, my wife was always there to love and encourage me, which really gave me strength. We had a lot of help from family, friends and church members to help us get through this. We couldn't have done it without them.

Two weeks after my last treatment my wife gave birth to our second daughter, Zoe, which means life. I struggled getting back and forth to the hospital and taking care of her but I did it and I have not looked back since then.

What is life like now? Now I'm 8 years cancer free and my face has healed. I don't look exactly like myself before cancer but it's close. People are still shocked to hear how much I went through because they

don't see that in my face, which I think, is a good thing. My smile is distorted and I have a big indentation in my cheek due to the missing tissue. I've tried a few cosmetic surgeries to improve the appearance and it has progressively gotten better but still not exactly where I want it. My biggest struggle today is the limited opening of my mouth (15 mm to be exact). It causes me issues with eating and replacing my missing tooth. Every dentist or prosthodontist I see struggles with helping me in this area.

Other than these cosmetic things, I've carried on with my life and do everything else that I want to do. I now have 3 beautiful daughters. I've progressed in my career in executive management and I've become a 1st degree black belt in Tae Kwan Do. All in all life is good and I am extremely grateful every year that I see.

My perspective is very different now; I never take time or my purpose for granted. I always try to remember that things could have gone the other way. If you ever doubt whether or not you can make it through the most difficult of circumstances, don't doubt yourself, because through faith, you can.

~ Garry Fielding
gfielding@gmail.com

There's A Lot Happening!

SPOHNC has been busy. Want to know what we've been up to? Here's a quick list below. More to come in 2018.

SPOHNC continues to seek out new and unique opportunities for partnership and collaboration, raising awareness of oral, head and neck cancer and SPOHNC.

What's New & Exciting?

- * *Your Cancer Game Plan continues into 2018*
- * *Immunotherapy Presentations are being given at SPOHNC Chapter meetings across the country*
- * *SPOHNC's "Eat Well Stay Nourished" cookbooks are being distributed to Head and Neck Oncology Professionals*
- * *Recipe Cards and Nutrition Posters are coming to Oncology Healthcare Professionals*



Visit the SPOHNC website at www.spoHnc.org

Head and Neck Cancer News

Long-term neurocognitive problems a concern for head and neck cancer survivors

November 24, 2017 - Head and neck cancer survivors are at risk for delayed neurocognitive deficits (NCD) for at least 2 years after radiotherapy or chemotherapy, according to a prospective longitudinal study.

The study assessed neurocognitive function and self-reported symptoms in 80 patients with head and neck cancer requiring definitive chemoradiotherapy or radiotherapy and 40 healthy controls. Significant differences were found between the performance of patients and controls in several domains, with patient deficits increasing over time.

“Findings indicate that neurocognitive function, although not immediately affected after treatment, progressively declines in the 2 years after definitive treatment with chemotherapy or radiation,” write Lori Bernstein (Princess Margaret Cancer Centre & University of Toronto, Ontario, Canada) and colleagues in *JAMA Otolaryngology–Head & Neck Surgery*.

The researchers conducted a 90-minute neurocognitive test battery at four time points: baseline (≤ 2 weeks before starting treatment), at the end of treatment (6 months after baseline), and 12 and 24 months after baseline. Test scores were converted into age-corrected z scores, and models were adjusted for baseline performance, age, education, and depression.

Overall, patients showed declines in global cognitive function, intellectual capacity, concentration/short-term attention span, verbal memory, executive function, and motor dexterity at 6, 12, and 24 months. However, patients and controls performed equally well in processing speed and visual memory.

While the patient and control cohorts had comparable frequencies of decline in all domains at 6 months, the proportion of individuals with declines at 24 months was higher among patients in the domains of intellectual capacity (27% of patients vs 3% of controls), verbal memory (21 vs 3%),

processing speed (12 vs 0%), executive function (26 vs 6%), and motor dexterity (10 vs 0%). In addition, 38% of patients exhibited impaired global cognitive function compared with none of the controls, a result the researchers describe as “especially concerning.”

Exploratory multivariable analyses conducted to assess possible prognostic factors for NCD found that lower education levels and higher baseline depression scores were the only patient characteristics prognostic for patients’ NCD across multiple domains. However, the researchers “noticed no consistent pattern to suggest reliable risk between receiving any particular chemotherapy regimen or radiation dose and having greater NCD.” Nonetheless, they conclude, “Strategies to reduce toxic effects and cognitive rehabilitation options should be available for [head and neck cancer] survivors.”

###

Head and Neck Cancer News

December JADA looks at dental disease in patients with head and neck cancer

Most patients with head and neck cancer have some level of dental disease when they begin radiation therapy, which highlights the importance of having a dental evaluation before starting treatment, according to research published in the December issue of *The Journal of the American Dental Association*.

For the article, “Dental Disease Before Radiotherapy in Patients with Head and Neck Cancer: Clinical Registry of Dental Outcomes in Head and Neck Cancer Patients,” authors evaluated the level of dental disease and factors associated with it in the patients before radiation therapy.

Researchers found a high rate of caries and periodontal disease in patients with head and neck cancer in an on going prospective cohort study.

Furthermore, less education, infrequent dental care, larger tumor size and not having dental insurance were associated with worse dental disease in head and neck cancer patients, said Dr. Michael Brennan,

corresponding author of the article and professor and chair of the department of oral medicine at the Carolinas Medical Center in Charlotte, North Carolina.

*“We admire your work
in the community...”*
~ Angela R.

*“I am grateful to learn of your
worthwhile and much needed
organization”*
~ Pat Z.

*“Thank you for your
valuable organization and
publications.”*
~ Barbara C.

*“You give me courage when I read your
newsletter. You’re all a blessing to me.”*
~ Lois R.

*This Holiday Season,
it's easy
to give
to SPOHNC!*

**SHOP
with**



**Go to AmazonSmile
Choose SPOHNC**

*as your charity
and Amazon
does the rest!*

SWEET NOVEMBER TREATS

from "Eat Well Stay Nourished
A Recipe and Resource Guide for Coping with Eating Challenges"

Sweet Potato Rumba

(from Volume One)

- 4 c. hot boiled sweet potatoes or yams, peeled
- ¼ c. melted butter or margarine
- ½ c. heavy cream
- ½ tsp. ground nutmeg
- ½ tsp. salt
- ¼ c. sugar
- 1 tsp. rum extract
- 1 Tbsp. melted butter or margarine
- 1 Tbsp. grated orange rind (optional)



Preheat oven to 400 degrees. Press sweet potatoes or yams through food mill or ricer. Add ¼ c. butter or margarine, cream, nutmeg, salt, sugar and rum extract. Beat until fluffy. Turn into buttered 1 quart casserole dish. Drizzle with 1 tablespoon melted butter or margarine. Sprinkle with orange rind. Bake 30 minutes or until lightly brown. Yields 6 servings. 264 calories/serving.

~ Member of PTRP, New York



Caramel Café Cheesecake

(from Volume Two)

- 2 pkg. (8 oz.) cream cheese
- ½ c. sugar
- 2 large eggs
- 1/3 c. brewed coffee (room temperature, double strength)
- 1 prepared graham cracker crust

Easy Caramel Dessert Topping

- 1 c. caramel dessert topping
- 2 Tbsp. double strength brewed coffee

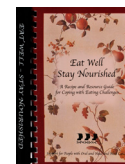
Preheat oven to 350 degrees. Beat cream cheese and sugar until well blended. Add eggs and coffee and mix well. Pour into crust. Bake for 35 to 49 minutes or until center is almost set. Cool completely and refrigerate for at least 3 hours or overnight.

To make double strength coffee: Brew 2 tablespoons ground coffee with ¾ cup water or add 2 teaspoons instant coffee to ¾ cup boiling water. Set aside to cool.

To make topping: heat caramel and coffee on low heat. Stir until mixed and warm. Store in refrigerator and reheat to serve. Serves 12. 493 calories/serving.

~ Michele B., Maryland

Eat Well Stay Nourished A Recipe and Resource Guide for Coping With Eating Challenges



\$20.00 includes shipping and handling.

- Recipes & Information About Eating Challenges and Nutrition
- Cancer Journeys of Survivors
- Suggestions and "Tips from the Pros"

Eat Well Stay Nourished A Recipe and Resource Guide for Coping With Eating Challenges Volume 2



\$23.00 includes shipping and handling.

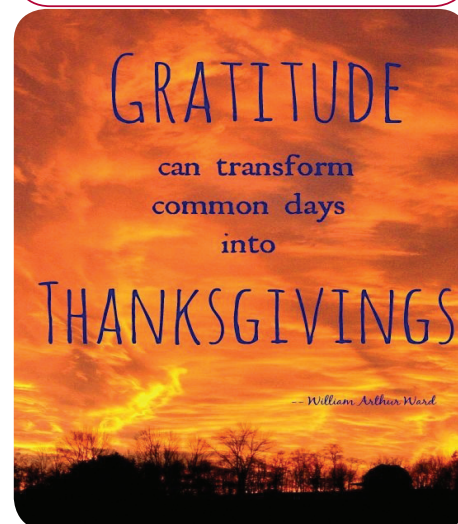
- New Recipes
- Chapter Devoted to Fortifying Foods
- Nutritional Information Included with Every Recipe

LIMITED TIME OFFER EXTENDED!

(while supplies last)

Two Volume Set

\$40.00 includes shipping and handling.



Connect with SPOHNC's "group" on Facebook

Give Thanks

Gratitude is Good for You

How often do you reflect on the good in your life? It's easy to take for granted the little things that make our lives better when we're facing challenges, like cancer, or dealing with other stressful situations. Thanksgiving is the obvious time to count your blessings, but cultivating a feeling of gratitude year-round can have big benefits: It can improve your physical and mental health.

Research over the past decade suggests that people who practice gratitude regularly have stronger immune systems, lower blood pressure and fewer symptoms of illness. They generally sleep better and can better tolerate their aches and pains. Gratitude encourages resilience after difficult experiences, and it strengthens relationships and promotes forgiveness.

Overall, people who are grateful tend to be happier and more optimistic, a characteristic linked to better immunity. They want to take care of themselves, so they exercise and eat for good health. "An attitude of gratitude improves our quality of life," says Dr. David Wakefield, psychologist. "Gratitude is an antidote for negative emotions like anxiety, depression and anger. Gratitude can help change our perspective in the midst of struggles."

What is gratitude?

In his essay "Why Gratitude Is Good," psychology professor Robert Emmons of the University of California, Davis, identifies two components of gratitude. The first is affirming that good exists in the world, and acknowledging that you have received benefits and gifts as a result of this goodness. The second is recognizing that these benefits and gifts come from others or a higher power.

Dr. Wakefield describes gratitude as an act of the will and a condition of the heart. "Gratitude is a perspective on your life as you journey through it. Gratitude is being thankful for the gifts and benefits you have received. It is a trait that we possess as a resiliency skill or that we learn with practice."

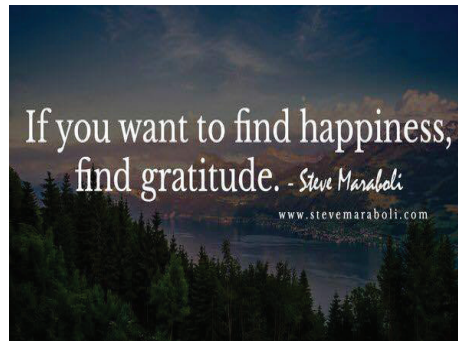
Gratitude and cancer

Cancer is one of the biggest health challenges

a person can face. It turns your life upside down in an instant, making your future unknown. With so much uncertainty and stress, how is it possible to be grateful? Recent research suggests that tapping into gratitude during tough times may be easier than expected. Adversity, it turns out, can make you more thankful, as you recognize the value of the people and experiences that have enriched your life.

"It is important to have gratitude during challenging times," Dr. Wakefield says. "It's one of our resiliency skills that will help us cope. Yet, if a cancer patient doesn't have gratitude it doesn't mean they are deficient. It just means it takes time."

Consider this scenario: You are undergoing cancer treatment, and you're feeling nauseous and are vomiting during a



week of chemotherapy. You're experiencing pain that prevents you from getting a good night's sleep. You're fatigued, just like 90 percent of cancer patients, and you have little energy to do the things you enjoy.

In the face of it all, you have to make a concerted effort to be grateful that your situation is not worse, Dr. Wakefield says. You can be grateful for the treatments you're receiving to help you get better, for the people who are supporting and caring for you, and for the team of doctors and clinicians who are working to fight your cancer.

"During challenging times it takes people time to adjust," Dr. Wakefield says. "It's important not to push people to a place they're not capable of being. People need time to adjust to trauma. After they have had to time to process their diagnosis, seek medical advice and treatment, and

decompress, then they can move on to resiliency skills, such as gratitude, that carry them during tough times."

The power of shared experience

Sometimes, sharing your experience with someone else can light the way toward gratitude.

How to cultivate gratitude

There are several ways to become more grateful for the gifts and benefits you've received in life. Try as many of these techniques as you need to so you can cultivate a spirit of gratitude and reap the health benefits that come with it.

- **Keep a gratitude journal:** Every day or every week, write down three to five things that made you grateful.
- **Write a thank-you note:** If there's someone who's made a difference in your life, write that person a thank you note, text or email and share how that person impacted your life. Consider writing yourself a thank-you note, too.
- **Thank someone mentally:** When you're crunched for time or low on energy, the next best thing to a thank-you note is to reflect on the positive effects someone has had on your life.
- **Recognize the positive:** Savor the little things that make your day brighter, whether it's an unexpected compliment or a beautiful sunset. By pausing to reflect, you'll be more mindful of the good around you.
- **Focus on intentions:** Think about how a person who brought good to your life made a conscious decision to do so. Also, consider the effort involved, whether it was that person's time or money.
- **Pray:** For people who are religious, prayer is a powerful tool to cultivate gratitude.
- **Meditate:** Sitting or lying down in stillness can help clear your mind so you can focus on why you are grateful. Meditate on an image or a word that represents why you are grateful.

continued on page 10

continued from page 9

Cancer patients can practice the above techniques in addition to the following ideas tailored specifically to their challenges:

- Visit a mental health counselor to sort through issues and develop a positive perspective.
- Spend time with cancer survivors to find encouragement and get advice.
- Talk to a someone with the same diagnosis to understand that others have gone through the same journey.
- Volunteer to help others who are struggling so you can have an impact while distracting yourself from your own challenges.
- Visit other cancer patients in the hospital and reach out to them. You'll feel grateful that you aren't in the hospital.
- Read books with a positive message, such as those written by cancer survivors.

Reprinted with permission from Cancer Treatment Centers of America website.

Chapter News

SPOHNC Welcomes New Chapters

SPOHNC currently has more than 130 Chapter support groups across the United States. If you are a SPOHNC Chapter Facilitator and your meeting day, time or location has changed, or if someone new is facilitating your group, please call SPOHNC at 1-800-377-0928 and let us know. Patient callers seeking support need to know about SPOHNC Chapters and the amazing support network that they can offer to those who are just beginning their cancer journey.

If you are a newly diagnosed patient and you're looking for folks to talk to, who understand what you're feeling, because they feel it too, find a SPOHNC Chapter in your area. Call SPOHNC today at 1-800-377-0928.

SPOHNC wishes a warm welcome to a few new Chapters across the United States.

We're glad you've joined our SPOHNC family!

SPOHNC Missoula, Montana, facilitated by Debra Rivey, LCSW, meets the 3rd Wednesday of every month, 12-1 pm, in the Community Cancer Care & Prevention Conference Room.

SPOHNC Lincoln, Nebraska is facilitated by Polly Ubben, and meets the 2nd Tuesday of the month from 11:45 am to 12:30pm, at St. Elizabeth Sports and Physical Therapy.

New Chapters are forming all the time. If you'd like to find out more about how to start a SPOHNC Chapter, contact SPOHNC. We provide materials, ongoing support and facilitator discussion and interaction to help you along the way. Join our SPOHNC family by attending a support group meeting today. We're here for you.



SPOHNC is Celebrating YOU!

Wishing you Sunshine and Happiness on your birthday & always

SPOHNC has many blessings to be grateful for this holiday season – one very special blessing is our dear friend, and SPOHNC family member on the West Coast, Valerie Targia. Valerie celebrated her birthday on November 22nd! 21 again!



Valerie has been a beloved member of our SPOHNC family for many years. She has been the Chapter Facilitator of our SPOHNC San Diego, California Chapter since 2001. Her unique variety of professional experience, coupled with her survivorship skills and her amazing sense of humor, have made her one of our most cherished Chapter Facilitators. Valerie has also been a volunteer for our National Survivor Volunteer Network match program, since 2003. She has supported so many patients in these two roles, and for her service, we are forever thankful. She also keeps us in stitches with her funny

e-mails to the SPOHNC national office! For instance, Valerie shared with us that for her birthday this year, she “went out for a gigantic Chinese buffet, and waddled out of the restaurant!” That’s quite a visual, especially given Valerie’s very petite frame!

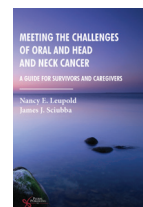


We wish our dear and very funny friend, Valerie, many more years of laughter and the zest for life that she exudes to all who cross her path.

Happy Birthday Valerie!



Meeting the Challenges of Oral and Head and Neck Cancer - A Guide for Survivors and Caregivers - Second Edition



“\$27.00 includes shipping and handling

Place your order today at

www.spo-hnc.org or call 1-800-377-0928

“A MUST for anyone with head and neck cancer. It is easy to understand, complete and comforting too. Thorough and informative - a good read and handy reference tool.”

Share SPOHNC on Facebook

CHAPTERS OF SPOHNC (125+ and growing!)

Contact SPOHNC at 1-800-377-0928 for Chapter information & Facilitator contact information

ALABAMA
BIRMINGHAM

ARIZONA
CHANDLER, MESA/GILBERT,
PHOENIX, SCOTTSDALE

ARKANSAS
HOT SPRINGS, NORTHWEST

CALIFORNIA
ENCINITAS, NEWPORT BEACH,
ORANGE-UCI, SACRAMENTO,
SAN DIEGO, SOUTH SAN FRANCISCO,
SANTA MARIA, STANFORD, VENTURA

COLORADO
COLORADO SPRINGS,
DENVER, PUEBLO

CONNECTICUT
NEW LONDON, NORWICH

DC
GEORGETOWN

FLORIDA
FT MYERS, GAINESVILLE,
JACKSONVILLE/ACC,
JACKSONVILLE/UFS, JUPITER,
LECANTO, MIAMI/UMS, NAPLES,
OCALA, PALM COAST/NORTHEAST,
SARASOTA, TAMPA, THE VILLAGES,
WINTER PARK

GEORGIA
ATLANTA-EMORY, AUGUSTA,
COLUMBUS, SAVANNAH

ILLINOIS
EVANSTON/HIGHLAND PARK,
MAYWOOD, MORRIS, SPRINGFIELD

INDIANA
FORT WAYNE, INDY-WEST,
SOUTH BEND, TERRE HAUTE,
WEST LAFAYETTE

IOWA
DES MOINES

KANSAS
KANSAS CITY, TOPEKA

LOUISIANA
BATON ROUGE, NEW ORLEANS

MARYLAND
BALTIMORE-GBMC, BALTIMORE-JHMI,
BETHESDA (*FOR MILITARY
AND BENEFICIARIES ONLY*),
LIBERTYTOWN

MASSACHUSETTS
BOSTON, CAPE COD,
MID-CAPE ON CAPE COD, DANVERS

MICHIGAN
ANN ARBOR, DETROIT,
ST. JOSEPH, WARREN

MINNESOTA
MINNEAPOLIS, ST. PAUL

MISSOURI
ST. LOUIS/SLUCC, ST. LOUIS/DPCC,
ST. PAUL

MONTANA
BOZEMAN, KALISPELL, MISSOULA

NEBRASKA
LINCOLN, OMAHA/MCC, OMAHA/NMC

NEW JERSEY
ENGLEWOOD, LONG BRANCH,
MORRISTOWN,
PRINCETON/UMC,
TOMS RIVER

NEW MEXICO
ALBUQUERQUE

NEW YORK
BUFFALO, MANHATTAN/BI,
MANHATTAN/MS, MANHATTAN/NYU,
MIDDLETOWN, NEW HYDE PARK,
ROCHESTER, STONY BROOK, SYOSSET,
WHITE PLAINS

NORTH CAROLINA
ASHVILLE, DURHAM/CHAPEL HILL,

OHIO
CINCINNATI, CLEVELAND,
DAYTON, LIMA, MENTOR

OREGON
MEDFORD

PENNSYLVANIA
DUNMORE, HARRISBURG,
HERSHEY, LANCASTER,
PHILADELPHIA/UNIV. PENN HOSPITAL,
YORK

RHODE ISLAND
WAKEFIELD

SOUTH CAROLINA
GREENVILLE (UPSTATE)

TENNESSEE
CHATTANOOGA, NASHVILLE

TEXAS
AUSTIN, DALLAS/BICMC,
DALLAS/NCC, DALLAS/UTS,
FORT WORTH, HOUSTON, McALLEN,
PLANO, SAN ANTONIO

VIRGINIA
CHARLOTTESVILLE, FAIRFAX,
NORFOLK

WASHINGTON
SEATTLE

WISCONSIN
APPLETON, EAU CLAIRE,
MADISON, MILWAUKEE



SUPPORT FOR PEOPLE WITH
 ORAL AND HEAD AND NECK CANCER
 P. O. BOX 53
 LOCUST VALLEY, NY 11560-0053

NON-PROFIT
 ORGANIZATION
 U.S. POSTAGE
 PAID
 LOCUST VALLEY, NY
 PERMIT NO. 28

ADDRESS SERVICE REQUESTED



*Remember to add
SPOHNC
 to your*



*Holiday Giving
 checklist.
Give Hope... Call Today
1-800-377-0928
 or go to spohnc.org*

Call 1-800-377-0928 to become a member and make a contribution by credit card or order online at www.spohnc.org

ANNUAL MEMBERSHIP

- \$30 Individual
- \$35.00 Foreign (US Currency)

CONTRIBUTIONS

- Booster, \$35+
- Donor, \$50+
- Sponsor, \$100+
- Patron, \$500+
- Benefactor, \$1,000+
- Founder, \$5,000+
- Leaders Circle, \$10,000+
- Visionary Circle \$15,000+

First time member _____ Returning member _____

Please Check: Survivor _____ Friend _____ Health Professional (Specialty) _____

City _____ State _____ Zip _____

Address _____

Address _____ Email Address _____

Name _____ Phone (_____) _____

Membership includes subscription to eight issues of *News From SPOHNC*

MEMBERSHIP APPLICATION
SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER, INC.
P.O. Box 53, Locust Valley, NY 11560

SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER (SPOHNC)